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## **Subgroups in epidemiological studies on spinal cord injury: Evaluation of international recommendations in the Swiss Spinal Cord Injury Cohort Study**

Hinrichs, Timo ; Proding, Birgit ; Brinkhof, Martin W G ; Gemperli, Armin

**Abstract:** **OBJECTIVE:** To test subgroups of a community-based sample of individuals with spinal cord injury, categorized by the application of current recommendations by the International Spinal Cord Society. **DESIGN:** Community survey. **PARTICIPANTS:** Individuals with traumatic and non-traumatic spinal cord injury residing in Switzerland. **METHODS:** Recommended subgroups of age, gender, years since injury, severity of injury and aetiology were tested against the following criteria: (i) distribution of participants across categories; (ii) within- and between-group variability with regard to selected outcomes of functioning and quality of life. **RESULTS:** Data-sets for 1,549 participants (28.5% women; mean age  $52 \pm 15$  years) were available for analyses. There was a number of participants in every subgroup, yet numbers were relatively small in the group with the shortest time since injury ( $< 1$  year;  $n = 23$ ) and in the oldest age group ( $> 76$ ;  $n = 94$ ). A high variability in some outcomes was detected between categories. All variables were predictive for most of the endpoints investigated. **CONCLUSION:** Recommended categorization could well fit the present sample. A minor concern was the low numbers of participants in some subgroups.

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## ORIGINAL REPORT

# SUBGROUPS IN EPIDEMIOLOGICAL STUDIES ON SPINAL CORD INJURY: EVALUATION OF INTERNATIONAL RECOMMENDATIONS IN THE SWISS SPINAL CORD INJURY COHORT STUDY

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**Objective:** To test subgroups of a community-based sample of individuals with spinal cord injury, categorized by the application of current recommendations by the International Spinal Cord Society.

**Design:** Community survey.

**Participants:** Individuals with traumatic and non-traumatic spinal cord injury residing in Switzerland.

**Methods:** Recommended subgroups of age, gender, years since injury, severity of injury and aetiology were tested against the following criteria: (i) distribution of participants across categories; (ii) within- and between-group variability with regard to selected outcomes of functioning and quality of life.

**Results:** Data-sets for 1,549 participants (28.5% women; mean age 52±15 years) were available for analyses. There was a number of participants in every subgroup, yet numbers were relatively small in the group with the shortest time since injury (<1 year; n=23) and in the oldest age group (≥76; n=94). A high variability in some outcomes was detected between categories. All variables were predictive for most of the endpoints investigated.

**Conclusion:** Recommended categorization could well fit the present sample. A minor concern was the low numbers of participants in some subgroups.

**Key words:** spinal cord injury; health survey; classification; statistical distributions; methodology; reporting; International Classification of Functioning, Disability and Health.

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## INTRODUCTION

Epidemiological analysis is concerned with describing and comparing the occurrence and patterns of health events between populations as well as across critical subgroups within populations (1). Analytical steps may include descriptive or inferential analyses, and both methods frequently use categorical variables to depict variation or derive conclusions (2). The

decision to categorize variables and the choice of categories necessitates some consideration and decision-making. Disadvantages of categorization may include information loss (especially in inferential analysis), while benefits include comparability across studies, which is also relevant with regard to future systematic reviews and meta-analyses. For nominal-scale variables, where a categorization is already given, researchers have to decide if certain categories should be collapsed; for continuous variables the number of categories and the category boundaries have to be determined (1). Categorization should result in a specified number of participants in every group and, ideally, an equal distribution between categories. With respect to the outcome under study, homogeneity within groups and heterogeneity between groups are desirable (1). Reducing or collapsing categories may increase the clarity of presentation and may also simplify subsequent statistical analyses; however, the resulting loss of detail may cover up important information or trends, and the reconstruction of detail by future researchers is impossible.

To facilitate comparability between epidemiological studies conducted in individuals with spinal cord injury (SCI), recommendations on how to categorize and report basic study sample characteristics were developed under the auspices of the International Spinal Cord Society (ISCoS) (ISCoS recommendations; (3, 4)). Such standards ease comparability of information across SCI studies and thus are of great relevance for epidemiological purposes. At the same time, the authors of the ISCoS recommendations acknowledged that further research may indicate where to improve the groupings in order to produce high homogeneity within groups and discrimination of outcomes between groups.

The aim of the present study was to test subgroups, resulting from the application of the ISCoS recommendations, among participants of the Community Survey performed by Swiss Spinal Cord Injury (SwiSCI). The resulting subgroups were tested for the following attributes: (i) distribution of participants across categories; (ii) variability, including: (a) homogeneity within groups and (b) heterogeneity between groups with regard to selected outcomes of domains of functioning and quality of life as cases in point.

## METHODS

*Study design*

SwiSCI is an ongoing observational cohort study that includes individuals, aged 16 years or older, who reside in Switzerland and have been diagnosed with traumatic or non-traumatic SCI. Exclusion criteria include congenital conditions leading to SCI, new SCI in the context of palliative care, and neurodegenerative disorders. Study design and recruitment procedures have been reported in detail elsewhere (5). SwiSCI was formally approved by the responsible regional research ethics committees. Written informed consent for use of questionnaire data was signed by all participants.

The present study refers to cross-sectional data collected between September 2011 and March 2013 in a community survey (5), using a mixed-mode design that included a combination of paper-based and web-based questionnaires, and telephone interviews as assessment methods. Potential participants were identified through cooperation with the national association for persons with SCI (Swiss Paraplegics Association), the SCI-specific home care organization ParaHelp, and 3 specialized SCI-rehabilitation centres. The part of the questionnaire that provided information for the present study was returned by 1,549 out of 3,144 individuals, a response rate of 49% (for details see (6)).

*Measures*

**Basic study sample characteristics.** The SwiSCI Community Survey included the following variables of the International Spinal Cord Injury Core Data Set (4): gender, date of birth, date of injury, aetiology of injury, and severity of injury. Years since injury and current age (at the time of the survey) were calculated. Aetiology of injury was classified as traumatic or non-traumatic. Severity of injury was assessed by questions on the level (tetraplegia, paraplegia) and the completeness (complete, incomplete) of the lesion. To approximate the American Spinal Injury Association Impairment Scale (AIS) these were combined to: complete tetraplegia (equivalent to C1–C8, AIS A), incomplete tetraplegia (C1–C8, AIS B, C or D), complete paraplegia (T1–S5, AIS A) and incomplete paraplegia (T1–S5 AIS B, C, or D) (4).

**Selected outcomes of domains of functioning and quality of life.** A number of different outcomes, covering domains of functioning according to the International Classification of Functioning, Disability and Health (ICF) and quality of life, were chosen as cases in point to evaluate variability between subgroups.

Five domains of functioning relevant for people with SCI were included in this study. For each of these domains a scale was developed that aggregates the available information for the relevant ICF categories in a metrically sound way, while keeping the conceptual components distinct (7). Items from the following existing instruments were integrated in the scales: the Spinal Cord Injury Secondary Conditions Scale (SCI-SCS) (8), Spinal Cord Independence Measure Self Report (SCIM-SR) (9) and the restriction scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) (10). The Rasch measurement model was applied, which estimates the parameters of a person's ability and an item's difficulty along the same logit scale, giving rise to equal interval units of measurement (11). Assumptions of unidimensionality, local independence of items, and group invariance across relevant groups were also tested. Five unidimensional outcomes (at chapter level or across chapters) were derived from survey questions, covering both the ICF component of "Body functions" and the ICF component of "Activities and Participation". The "Mental functions" (ICF chapter b1) scale consists of 7 items (range –4 to 5 logits), the "Functions of body systems" (ICF chapters b2–b8) scale integrates 13 items (range –4 to 5 logits), the "Mobility" (ICF chapter d4) scale constitutes of 8 items (range –4 to 4 logits), the "Self care" (ICF chapter d5) scale encompasses 6 items (–4 to 9 logits) and the "Involvement in life situations" (ICF chapters d6–d9) scale consists of 8 items (range –3 to 6 logits). Higher scores represent lower levels of functioning. Each scale has shown to be invariant across age, gen-

der, and SCI aetiology and provides interval-scaled data for further epidemiological analyses (7).

Quality of life was assessed by 4 selected items of the WHO-QOL BREF questionnaire (12). The WHO-QOL BREF uses a 5-point Likert scale to rate quality of life (ranging from "very poor" to "very good"), satisfaction with personal health, with the ability to perform daily living activities, and with personal relationships (ranging from "very dissatisfied" to "very satisfied").

*Statistical analyses*

Continuous variables were categorized according to ISCoS recommendations (3). Age (at time of survey) was split into 15-year intervals. Time since injury was split into an interval of less than 1 year, an interval of 1–5 years, and 5-year intervals thereafter. The highest age or time since injury interval with an acceptable number of cases was found to be older than 75 years and more than 40 years since injury, respectively. The distribution of study participant characteristics across categories was evaluated for continuous variables using summary statistics, including number of non-missing values, frequencies, mean and standard deviation (SD), median, as well as minimum and maximum per category.

As a measure of data clustering, the variability of continuous outcomes across categories of predictor variables was assessed by comparing the SD in outcomes between strata. Minimum, maximum and standard deviation of the stratum specific variability were computed, along with *p*-values from Levene's test for the equality of variances between categories. Heterogeneity between groups was assessed through one-way analysis of variance (ANOVA) for continuous outcomes and via Kendall's tau for testing the association between ordinal variables. *p*-values for the ANOVA were derived via simulation of the data given actual group sizes and estimated standard deviations under the null hypothesis using 5,000 replications. This was computed using the simanova package in Stata. The variability of continuous outcomes across categories of predictor variables was further depicted graphically in scatterplots comparing mean per strata with actual measurements.

Rasch scores were derived using the TAM packed version 1.0-3.18-1 in R version 3.1.0. All other statistical analyses and data preparation were performed with Stata version 13.1 (StataCorp LP, College Station, TX, USA).

## RESULTS

A total of 1,549 individuals participated in the study, of whom 71.5% were male. The median age was 52 (interquartile range (IQR) 42–63) years. Detailed participant characteristics and their distribution across categories are shown in Table I. Most study participants were in the age category 46–60 years (36.9%), with only a few being 30 years or younger, or older than 75 years (8.3% and 6.1%, respectively). The age distribution was skewed to the left in the youngest, 16–30 years, age group (median age 26 years) and skewed to the right in the oldest, ≥ 76 years, age group (median age 79 years). All other age categories showed a uniform distribution of age within strata. Time since injury was less than 25 years in over 75%, and less than one year in 1.5% of participants. Within each 5-year period the data were uniformly distributed. Seventy-eight percent of participants had a traumatic cause of SCI. The distribution of participants across severity level was between 10.0% (tetraplegia complete) and 37.2% (paraplegia incomplete).

Summary statistics of the functioning outcomes are shown in Table II. There was a significant difference in variability

Table I. Summary statistics and distribution of study sample according to recommended categories n = 1,549

Parameter/Category	n (%) <sup>a</sup>	Mean (SD)	Median (min; max)
Age			
Missing	0	—	—
Non-missing	1,549 (100.0)	52.3 (14.8)	52 (16; 94)
16–30 years	129 (8.3)	25.5 (3.7)	26 (16; 30)
31–45 years	377 (24.3)	39.2 (4.0)	40 (31; 45)
46–60 years	571 (36.9)	52.8 (4.4)	53 (46; 60)
61–75 years	378 (24.4)	66.8 (4.0)	67 (61; 75)
76 or older	94 (6.1)	80.6 (4.0)	79 (76; 94)
Time since injury			
Missing	27 (1.7)	—	—
Non-missing	1,522 (98.3)	16.8 (12.7)	13 (0; 75)
<1 years	23 (1.5)	0.0 (0.0)	0 (0; 0)
1–5 years	340 (22.3)	2.9 (1.4)	3 (1; 5)
6–10 years	258 (17.0)	7.9 (1.4)	8 (6; 10)
11–15 years	215 (14.1)	12.6 (1.4)	12 (11; 15)
16–20 years	165 (10.8)	18.1 (1.4)	18 (16; 20)
21–25 years	160 (10.5)	22.8 (1.4)	23 (21; 25)
26–30 years	124 (8.1)	27.9 (1.4)	28 (26; 30)
31–35 years	90 (5.9)	32.8 (1.4)	32 (31; 35)
36–40 years	62 (4.1)	37.7 (1.4)	37 (36; 40)
≥41 years	85 (5.6)	45.8 (5.3)	45 (41; 75)
Gender			
Male	1,107 (71.5)		
Female	442 (28.5)		
Missing	0		
Severity of injury			
Tetraplegia complete	160 (10.3)		
Tetraplegia incomplete	314 (20.3)		
Paraplegia complete	486 (31.4)		
Paraplegia incomplete	577 (37.2)		
Missing	12 (0.8)		
Aetiology			
Traumatic	1,202 (77.6)		
Non-traumatic	332 (21.4)		
Missing	15 (1.0)		

<sup>a</sup>Relative frequencies for categories of age and years since injury were evaluated for the complete cases. Relative frequencies for all other variables were evaluated for the total study population.

SD: standard deviation; Min: minimum; Max: maximum.

detected across categories of age for the “Involvement in life situations” outcome, across categories of years since injury for the “Mental functions” outcome, and between genders for the “Self care” outcome (Table III). Most outcomes displayed significant differences in variability across categories of severity of injury, except “Mental functions” and “Functions of body systems”. Amongst all other outcomes and categories of predictors the variability was fairly homogenous.

Heterogeneity between groups was high between all outcomes and all categorized parameters, except in “Mental functions” vs age or aetiology, “Functions of body systems” vs years since injury or severity of injury, “Self care” vs gender or aetiology, and “Mobility” vs aetiology (Table III). Recommended categories for age and time since injury appropriately reflected the distribution of the data as well as trends in key outcomes (Fig. 1). All parameters were highly predictive of at least 4 of the 5 outcomes and most distinctive of “Mobility” and “Involvement in life situations”. The ratings of quality of

Table II. Summary statistics of continuous functioning outcomes

Outcome	n	Mean (SD)	Median (Q1; Q3)	Min; Max
Mental functions	1,515	0.0 (1.6)	0.0 (–0.9, 1.2)	–4.2; 4.8
Functions of body systems	1,506	0.0 (1.1)	0.1 (–0.6, 0.7)	–2.7; 4.3
Mobility	1,508	0.1 (1.9)	0.1 (–1.4, 1.3)	–4.1; 4.6
Self care	1,530	0.4 (2.3)	0.3 (–1.5, 1.8)	–2.4; 7.0
Involvement in life situations	1,487	0.2 (1.8)	0.1 (–1.1, 1.3)	–3.0; 6.5

SD: standard deviation; Q1, Q3: lower and upper quartile.

life, satisfaction with health and ability to perform daily living activities showed high association with most investigated parameters (Table IV). No association was found between any parameter and satisfaction with personal relationships.

## DISCUSSION

The comparability of reported participant characteristics with other studies can help to determine selection bias and to convince the reader that the population included in the study, to the extent possible, is representative of the population intended to study. For the present study, we therefore defined comparability with other studies as top priority for categorization and applied the ISCoS recommendations on standardized reporting to the SwiSCI Community Survey sample. For the comparison with other epidemiological studies conducted in populations with SCI, this seems appropriate, on the condition that the recommendations will be broadly adopted by future studies in this field. Currently, the comparability with past studies remains limited by the inconsistency in reporting, as shown by an overview of randomly chosen past publications (see Table V) and as previously stated by the authors of the International Perspectives on Spinal Cord Injury (IPSCI), a report recently published by WHO and ISCoS (13). The authors of the IPSCI report strongly suggest using the ISCoS recommendations in future studies and the editors of *Spinal Cord*, the scientific journal of ISCoS, recently made use of the recommendations mandatory for publications in their journal (14). However, in studies where comparisons with the general population or populations with a different index disease are intended, other categorizations might be preferable. Unfortunately there is no consensus on how to categorize data for reporting. To give some examples, a publication of the cohort profile of the Swiss National Cohort reports the following age groups: 0–9, 10–29, 30–64, 65–84, ≥85 years (15); the Global Burden of Disease reports the age groups: 0–4, 5–14, 15–59, ≥60 years (16); and the World Report on Disability, which is not based on its own data collection, reports 2 different categorizations: 18–49, 50–59, ≥60 years, and 0–14, 15–59, ≥60 years (17). Choice of categories might also be determined by the subject under study. As an example, studies on labour market participation would usually be limited to individuals of working age (18–64 years) and the use of the age categories recommended by ISCoS would therefore not be very convenient (e.g. 18).



Table III. Variability and heterogeneity in outcomes across strata of recommended categories for population parameters

Parameter [number of categories] <sup>a</sup>	Outcome	Variability		Heterogeneity	
		Min; Max (SD) <sup>b</sup>	<i>p</i> -value <sup>c</sup>	MS within; between <sup>d</sup>	<i>p</i> -value <sup>e</sup>
Age [5]	Mental functions	1.46; 1.66 (0.08)	0.310	2.57; 5.82	0.051
	Functions of body systems	0.99; 1.11 (0.04)	0.274	1.09; 7.39	<0.001
	Mobility	1.68; 2.10 (0.14)	0.090	3.48; 34.16	<0.001
	Self care	1.90; 2.42 (0.20)	0.051	5.33; 33.45	<0.001
	Involvement in life situations	1.65; 2.14 (0.19)	0.004	3.25; 56.40	<0.001
Years since injury [10]	Mental functions	1.29; 1.81 (0.16)	0.003	2.53; 7.36	0.003
	Functions of body systems	0.78; 1.15 (0.11)	0.279	1.10; 1.50	0.136
	Mobility	1.66; 2.00 (0.12)	0.232	3.52; 13.27	<0.001
	Self care	2.15; 2.56 (0.14)	0.397	5.34; 15.95	0.003
	Involvement in life situations	1.40; 1.91 (0.16)	0.385	3.36; 7.28	0.013
Gender [2]	Mental functions	1.58; 1.61	0.806	2.56; 38.23	<0.001
	Functions of body systems	1.05; 1.05	0.709	1.11; 8.59	0.007
	Mobility	1.86; 1.91	0.805	3.53; 59.12	<0.001
	Self care	2.10; 2.41	<0.001	5.40; 2.54	0.466
	Involvement in life situations	1.69; 1.88	0.027	3.36; 49.04	<0.001
Severity of injury [4]	Mental functions	1.50; 1.67 (0.06)	0.148	2.57; 8.56	0.020
	Functions of body systems	0.97; 1.10 (0.06)	0.185	1.12; 1.16	0.384
	Mobility	1.36; 2.12 (0.28)	<0.001	2.89; 343.94	<0.001
	Self care	1.56; 2.69 (0.44)	<0.001	3.89; 763.17	<0.001
	Involvement in life situations	1.58; 1.94 (0.15)	0.003	3.05; 170.03	<0.001
Aetiology [2]	Mental functions	1.59; 1.68	0.070	2.59; 9.31	0.064
	Functions of body systems	1.04; 1.08	0.486	1.10; 31.11	<0.001
	Mobility	1.88; 1.93	0.372	3.58; 10.22	0.093
	Self care	2.13; 2.37	0.050	5.40; 0.02	0.950
	Involvement in life situations	1.77; 1.86	0.261	3.38; 30.99	<0.001

<sup>a</sup>Categories are listed in Table I.<sup>b</sup>Min, Max (SD): minimum, maximum and standard deviation of standard deviations in outcome across categories (not reported for gender and aetiology, which have only 2 categories).<sup>c</sup>*p*-value from Levene's test statistic for the equality of variances between the categories.<sup>d</sup>MS within; between: within and between categories mean square.<sup>e</sup>*p*-value from simulated (1-way) analysis of variance allowing unequal group variances.

In our sample, recommended cut-offs for creating categories for given parameters were generally supported by the overall value distribution. Only the lower extreme of time since injury (<1 year) and upper extreme of age ( $\geq 76$  years) contained low numbers of individuals, which may increase the risk of chance findings and erroneous inference regarding outcomes in these groups. Recommended categorizations for time since injury and age were therefore less appropriate for our community survey, because persons still receiving first inpatient rehabilitation (in their first year after SCI) were not invited to participate, and the source population contained only small numbers of people aged  $\geq 76$  years (6). The merging of these

extreme categories to adjacent levels is likely to improve inference and also maintains comparability with results from other studies on the aggregated level.

A successful stratification should lead to fairly homogenous groupings; groups that are very disparate with respect to the outcome under study should not be merged. This study demonstrated well-distributed outcomes across all strata. The exception being the categories of severity of injury, which is grouped based on clinical reasoning and should not be altered. Heterogeneity between groups is not considered necessary for a good categorization, as this depends mainly on the predictive power a measurement has in general. Still, the

Table IV. Association between categorized predictors and quality of life outcomes

Parameter [number of categories] <sup>a</sup>	Quality of life		Satisfaction with health		Satisfaction with ability to perform daily living activities		Satisfaction with personal relationships	
	tau-b <sup>b</sup>	<i>p</i> -value	tau-b	<i>p</i> -value	tau-b	<i>p</i> -value	tau-b	<i>p</i> -value
Age [5]	-0.09	<0.001	-0.02	0.349	-0.11	<0.001	0.01	0.604
Years since injury [10]	0.08	<0.001	0.09	<0.001	0.09	<0.001	0.04	0.074
Gender [2]	-0.04	0.079	-0.08	<0.001	-0.01	0.700	0.24	0.314
Severity of injury [4]	-0.01	0.616	-0.05	0.014	0.06	0.003	-0.03	0.170
Aetiology [2]	-0.09	<0.001	-0.16	<0.001	-0.12	<0.001	-0.02	0.339

<sup>a</sup>Categories are listed in Table I.<sup>b</sup>Kendall's tau-b for association between categorical outcomes.

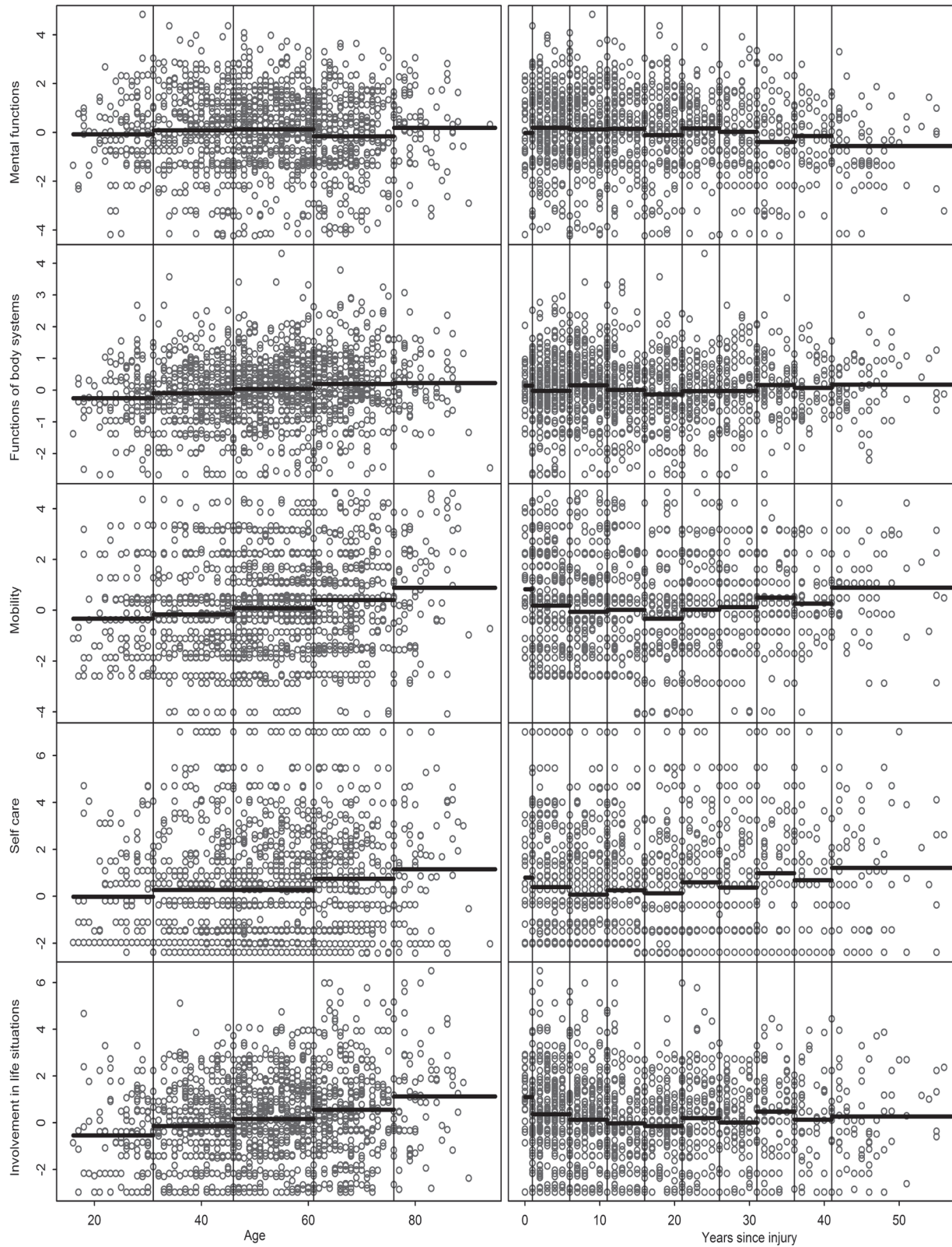


Fig. 1. Distribution of outcomes across strata of recommended categories for continuous population parameters. *Vertical grid lines*: recommended cut-off of continuous parameters age (in years) and years since injury. *Horizontal bold lines*: averaged outcome per category of age or years since injury, respectively. Not shown are 2 outliers for years since injury of 61 and 75 years, respectively.

Table V. Reporting of basic study sample characteristics in randomly chosen studies conducted in populations with spinal cord injury (sorted by year of publication and alphabetically by first author name)

Authors/year	Feng et al. 2011 (22)	Krause & Saunders 2012 (23)	Perrier et al. 2012 (24)	Sale et al. 2012 (25)	Model SCI Systems Annual Statistical Report 2013 (26)	Wang et al. 2013 (27)	Kivisild et al. 2014 (28)
Population/data source	Medical records of patients with TSCI admitted to the Tianjin Medical University General Hospital (China)	Adults with TSCI of at least 1-year duration recruited through a specialty hospital in the Southeast USA	Ontarians (Canada) with TSCI requiring assistance with mobility outside, recruited from databases of 4 rehabilitation centres and through advertisement	Follow-up of a sample of first admission TSCI patients discharged between 1997 and 1999 from 24 Italian centres	Patients receiving care following SCI in a network of regional SCI Model Systems located at major medical centres throughout the USA	Medical records of all patients with TSCI admitted to hospitals in the Anhui from the Province (China) between 2007 and 2010	Estonian-speaking TSCI patients from the Estonian TSCI database
Age, years	Age at injury: categories 15–24, 25–34, ..., 55–64, ≥65	Current age: mean, SD; categories 18–34, 35–44, ..., 65–74, ≥75	Current age: mean, SD	Age at follow-up: mean, SD, median, interquartile range	Age at injury: mean, SD, range; frequencies for every single year; for cross-tabulation with aetiology groups: categories 0–15, 16–30, ..., 61–75, ≥76	Age at injury: categories 0–15, 16–30, 31–45, 46–60, >60	Age at injury: mean, SD
Time since injury, years	Not applicable	Mean, SD	Mean, SD	Time since discharge: mean, median, range	Post-injury year: 1, 5, 10, 15, 20, 25, 30, 35, 40	Not applicable	Mean, SD, range
Length of stay	Not reported	Not reported	Not reported	Not reported	Median days hospitalized in the System's Acute Care Unit and in the System's Rehab Unit	Range, median (days)	Not reported
Year of injury	1998–2000, 2001–2003, 2004–2006, 2007–2009	Not reported	Not reported	Not reported	1973–1979, 1980–1984, ..., 2005–2009, 2010–2013	Not reported	Not reported
Gender	Male, female	Male, female	Male, female	Male, female	Male, female	Male, female	Male, female
Severity of injury	Lesion level: every single level from C1–L5; S1–5 as a group; for cross-tabulation with aetiology: cervical, thoracic, lumbar, sacral AIS: A, B, C, D Impairment category: tetraplegia, complete; tetraplegia, incomplete; paraplegia, complete; paraplegia, incomplete	Lesion level/impairment category: C1–C4, non-ambulatory; C5–C8, non-ambulatory; non-cervical, non-ambulatory; non-ambulatory	Lesion level/AIS: C1–C4, AIS A, B or C; C5–C8, AIS A, B or C; T1–S5, AIS A, B or C; AIS D	Impairment category: paraplegia, tetraplegia AIS: A or B; C, D or E	Lesion level: every single level (C1–S5) Impairment category: tetraplegia, complete; tetraplegia, incomplete; tetraplegia, minimal deficit; paraplegia, complete; paraplegia, incomplete; minimal deficit AIS: A, B, C, D, E AIS motor index score total: mean, SD, range	Lesion level: cervical, thoracic, lumbosacral AIS: A, B, C, D	AIS: A or B, C or D, sensory symptoms only
Place of residence	Not applicable	Super-rural, rural, urban	Not reported	Living at home (yes, no)	Private hospital, nursing home, group living, correctional institution, hotel/motel, homeless, assisted living, other	Not reported	Not reported
Associated injuries	Not reported	Not reported	Not reported	Not reported	Yes, no	Head injuries, limb or pelvic fractures, fractures of ribs, others	Not reported

Table V *contd.*

Authors/year	Feng et al. 2011 (22)	Krause & Saunders 2012 (23)	Perrier et al. 2012 (24)	Sale et al. 2012 (25)	Model SCI Systems Annual Statistical Report 2013 (26)	Wang et al. 2013 (27)	Kivisild et al. 2014 (28)
Spinal surgery	Not reported	Not reported	Not reported	Not reported	Yes, no	Decompression, decompression + internal fixation, decompression + internal fixation + fusion	Not reported
Aetiology	TSCI only: low fall, high fall, motor vehicle collision, falling object, collision of head against object, injury involving machinery, sports, massage	TSCI only	TSCI only	TSCI only	Vehicular, violence, sports or recreation, falls, other, unknown	TSCI only: transport, struck by object, fall from height, low fall, others (assault, sport-related injury)	TSCI only

TSCI: traumatic spinal cord injury; AIS: American Spinal Injury Association impairment scale; SD: standard deviation.

grouping may enforce or weaken the magnitude in statistical significance of associations. It should be noted that most statistical methods are based on the precondition that categories were chosen independently of the outcome (1), therefore the presented considerations and methods should not be used to manipulate the choice of categories towards a desired direction. Using the ISCoS recommendations could therefore also be considered as a way to avoid any tampering with study results.

To investigate variability we chose outcomes that have previously been considered as relevant in the rehabilitation of individuals with SCI (19–21). However, these outcomes merely serve as cases in point to illustrate our statistical considerations; the choice does not imply a rating of relevance. It should also be noted that our considerations on categorization refer only to the descriptive presentation of basic participant characteristics; for advanced analyses it is usually not recommended to group continuous data, but to use them in their original form (or as, for example, transformations, splines or polynomials). Our choice of variables to describe basic participant characteristics was performed from the perspective of comparability of information within and across SCI populations and therefore based on the International Spinal Cord Injury Core Data Set (4). For future research, it would be worthwhile to examine whether these variables are sufficient and adequate to act as effect modifiers in understanding functioning in SCI.

Limitations of the current study include that the self-report measure of severity of injury was crude and cannot be considered equivalent to direct examination. However, linkage with medical records demonstrated substantial agreement between previously documented and self-reported severity (6). An in-depth analysis of survey non-response was conducted to quantify potential response bias (6). There was no relevant response bias in relation to demographic variables (age, gender) and lesion level. Existing bias, both in relation to participants' membership of the Swiss Paraplegics Association and in relation to time since injury, had only minor impacts on key outcomes of the survey (for details see (6)).

In conclusion, this study showed that it is feasible to apply ISCoS recommendations to the SwiSCI Community Survey sample. The only issue of concern were categories with a low number of participants (time since injury < 1 year and age ≥ 76 years). The many categories defined for age (15-year intervals) and years since injury (5-year intervals) were found suitable for this large data-set, but may not be similarly appropriate in all cases. In case of specific research questions, e.g. on work participation or when a comparison with specific studies conducted in the general population is intended, it might be preferable to deviate from recommendations and use different, well-targeted and pre-specified age groups.

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## REFERENCES

- Greenland S, Rothman KJ. Fundamentals of epidemiologic data analysis. In: Rothman KJ, Greenland S, Lash TL, editors. *Modern epidemiology*. Philadelphia: Lippincott Williams & Wilkins; 2008.
- Kirkwood BR, Sterne JAC. *Essential medical statistics*. 2nd edn. Malden, MA, USA: Blackwell Science; 2003.
- DeVivo MJ, Biering-Sorensen F, New P, Chen Y. Standardization of data analysis and reporting of results from the International Spinal Cord Injury Core Data Set. *Spinal Cord* 2011; 49: 596–599.
- DeVivo M, Biering-Sorensen F, Charlifue S, Noonan V, Post MWM, Stripling T, et al. International Spinal Cord Injury Core Data Set. *Spinal Cord* 2006; 44: 535–540.
- Post MWM, Brinkhof MWG, von Elm E, Boldt C, Brach M, Fekete C, et al. Design of the Swiss Spinal Cord Injury Cohort Study. *Am J Phys Med Rehabil* 2011; 90: S5–S16.
- Brinkhof MWG, Fekete C, Chamberlain JD, Post MWM, Gemperli A. Swiss national community survey on functioning after spinal cord injury: protocol, characteristics of participants and determinants of nonresponse. *J Rehabil Med* 2016; 48: 120–130.
- Prodinger B, Ballert C, Brach M, Brinkhof MWG, Cieza A, Hug K, et al. Toward standardized reporting for a cohort study on functioning: the Swiss Spinal Cord Injury Cohort Study. *J Rehabil Med* 2016; 48: 189–196.
- Kalpajian CZ, Scelza WM, Forchheimer MB, Toussaint LL. Preliminary reliability and validity of a Spinal Cord Injury Secondary Conditions Scale. *J Spinal Cord Med* 2007; 30: 131–139.
- Fekete C, Eriks-Hoogland I, Baumberger M, Catz A, Itzkovich M, Luthi H, et al. Development and validation of a self-report version of the Spinal Cord Independence Measure (SCIM III). *Spinal Cord* 2013; 51: 40–47.
- Post MWM, van der Zee CH, Hennink J, Schafrat CG, Visser-Meily JM, van Berlekom SB. Validity of the Utrecht Scale for Evaluation of Rehabilitation-Participation. *Disabil Rehabil* 2012; 34: 478–485.
- Rasch G. Probabilistic models for some intelligence and attainment tests. Copenhagen: Danish National Institute for Educational Research; 1960.
- Skevington SM, Lotfy M, O'Connell KA. The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group. *Qual Life Res* 2004; 13: 299–310.
- Bickenbach J, Officer A, Shakespeare T, von Groote P, editors. *International Perspectives on Spinal Cord Injury*. Geneva: WHO; 2013.
- Wyndaele JJ. Standardization of reporting data in the 'Spinal Cord' journal. *Spinal Cord* 2012; 50: 483.
- Bopp M, Spoerri A, Zwahlen M, Gutzwiller F, Paccaud F, Braun-Fahrlander C, et al. Cohort Profile: the Swiss National Cohort – a longitudinal study of 6.8 million people. *Int J Epidemiol* 2009; 38: 379–384.
- World Health Organization. The global burden of disease: 2004 update. Geneva: WHO; 2008.
- World Health Organization. World report on disability. Geneva: WHO & The World Bank; 2011.
- Marti A, Reinhardt JD, Graf S, Escorpizo R, Post MWM. To work or not to work: labour market participation of people with spinal cord injury living in Switzerland. *Spinal Cord* 2012; 50: 521–526.
- Stover SL, DeLisa JA, Whiteneck GG, editors. *Spinal cord injury – clinical outcomes from the Model Systems*. Gaithersburg, MD, USA: Aspen Publishers Inc.; 1995.
- Post MWM, Kirchberger I, Scheuringer M, Wollaars MM, Geyh S. Outcome parameters in spinal cord injury research: a systematic review using the International Classification of Functioning, Disability and Health (ICF) as a reference. *Spinal Cord* 2010; 48: 522–528.
- Cieza A, Kirchberger I, Biering-Sorensen F, Baumberger M, Charlifue S, Post MWM, et al. ICF Core Sets for individuals with spinal cord injury in the long-term context. *Spinal Cord* 2010; 48: 305–312.
- Feng HY, Ning GZ, Feng SQ, Yu TQ, Zhou HX. Epidemiological profile of 239 traumatic spinal cord injury cases over a period of 12 years in Tianjin, China. *J Spinal Cord Med* 2011; 34: 388–394.
- Krause JS, Saunders LL. Socioeconomic and behavioral risk factors for mortality: do risk factors observed after spinal cord injury parallel those from the general USA population? *Spinal Cord* 2012; 50: 609–613.
- Perrier MJ, Latimer-Cheung AE, Ginis KA. An investigation of seasonal variation in leisure-time physical activity in persons with spinal cord injury. *Spinal Cord* 2012; 50: 507–511.
- Sale P, Mazarrella F, Pagliacci MC, Aito S, Agosti M, Franceschini M. Sport, free time and hobbies in people with spinal cord injury. *Spinal Cord* 2012; 50: 452–456.
- National Spinal Cord Injury Statistical Center. Complete Public Version of the 2013 Annual Statistical Report for the Spinal Cord Injury Model System. Birmingham, AL, USA: National Spinal Cord Injury Statistical Center; 2013.
- Wang HF, Yin ZS, Chen Y, Duan ZH, Hou S, He J. Epidemiological features of traumatic spinal cord injury in Anhui Province, China. *Spinal Cord* 2013; 51: 20–22.
- Kivisild A, Sabre L, Tomberg T, Ruus T, Korv J, Asser T, et al. Health-related quality of life in patients with traumatic spinal cord injury in Estonia. *Spinal Cord* 2014; 52: 570–575.